

# **Report on the King County Planning Focus Groups 2005-2009 Developmental Disabilities Plan**

Prepared for the King County  
Developmental Disabilities Division

Submitted by:

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## **Table of Contents**

Introduction and Summary	Page 1
Families with Children from Birth to Three	Page 5
Families of School Age Children	Page 9
Families of Transition Age Youth	Page 13
Families of Working Age Adults	Page 18
Older Families of Adults	Page 23
Residential Providers	Page 28
Birth to Three Providers	Page 33
Community Access Providers	Page 38
Employment Providers	Page 42
Community Protection Providers	Page 48
Self Advocates	Page 52
Case Resource Managers	Page 55
School Teachers and Administrators	Page 60

## **Introduction**

This is a report on information gathered from focus groups held in King County in October, November and December 2004. The purpose of the focus groups was to provide the King County Developmental Disabilities Division with information to assist in the development of a new four year plan beginning July 2005. The goal of the focus group was to obtain a variety of perspectives on service needs and generate ideas on how to address the needs within the County's mission and values.

There were 68 participants organized into thirteen sessions of parents, providers, self-advocates, case resource managers and educators. The sessions were led by a facilitator and a scribe to record participant responses to a series of five to eight questions. The questions were designed to elicit comparable information from all of the sessions, although their language was modified to ensure that the questions were relevant given the composition of each session. The sessions lasted two hours.

The number of participants and the broad variety of groups generated a large volume of information on how people think and feel about the nature and direction of services for people with developmental disabilities in King County.

## **Summary**

Participants described an environment and a service delivery system that is on the decline, reduced funding for valued services and reduced flexibility. They wanted to see improved collaboration, increased communication, and more training. Participants wanted increased opportunities for employment.

## **General Themes**

There was a consensus of opinion on several themes among the groups.

- The need for improved collaboration, communication and information between families, providers and service systems.
- Concern that people's needs are not being met and the assessment tools do not accurately reflect the needs of individuals.
- Fear that values and quality are being compromised by waivers and policies.
- The loss of funding and flexibility will affect the services to families and people with developmental disabilities, in particular, people with the most significant disabilities.

- Training and technical assistance are critical to maintaining competence of staff and knowledge of the best practices.
- There needs to be more opportunities for employment. Too many people are unemployed.

The following summarizes the themes by group.

### **Families**

- Families are satisfied with the services they received from King County Developmental Disabilities. They would like to see more communication and collaboration between systems to make it easier for them to navigate multiple systems.
- Families would like to see the County provide more information to them on the resources that are available and the role of the county, state, school and providers.
- Families are concerned with the isolation of their sons and daughters and would like to see programs that help people with disabilities find friends and have more social opportunities in the community.
- Families are worried about the lack and loss of services and funding for themselves and families receiving nothing.
- Families want their sons and daughters to have jobs and get the support that they need to be successful.

### **Service Providers**

- Providers are concerned that people, especially those with the most significant disabilities, will not be served due to loss of funding and flexibility caused by new waivers and policies. Examples are the loss of block grant funding to employment and the hours and rate for community access that will affect the quality and capacity of providers.
- Providers want more information, collaboration, and communication from the County.
- Providers are concerned with the loss of values, quality and individual planning. They fear that the focus is on quantity rather than quality and a shift to groups rather than the individual.
- Providers want more opportunities for training and access to best practices.
- Providers would like to see a vendor rate increase.

### **Self-Advocates**

- Self-advocates are pretty satisfied with services although they are sometimes limited by staff availability.

- Self-advocates think supported employment is good, but it's hard to find and keep jobs.
- Self-advocates want more training and conference opportunities.
- Self-advocates want more housing and transportation options.
- Self-advocates do not want any more reductions in services.

## **Teachers**

- Teachers have limited contact with County services and resources but were very pleased with those they have utilized, including:
  - Benefits Specialists
  - Parent Coalition
  - Work Training
  - WISE
- Teachers are frustrated by the lack of capacity in the adult service system.
- They feel that the Department of Social and Health Services Division of Vocational Rehabilitation (DVR) and the Division of Developmental Disabilities (DDD) have arbitrary and ever-changing criteria for funding eligibility that frequently translates into no services for their students.
- They are concerned about the increasing numbers of students who do not have jobs after graduation.
- They would like to be able to receive more training on job development and employment training but do not have enough time or resources to attend training.
- Teachers observe that the adult service system in general seems fragmented with no one place to go to receive necessary information.

## **Case Resource Managers**

- Case managers are concerned that choices for people with developmental disabilities are decreasing.
- Case managers want more collaboration with County staff on individuals and a more pro-active working relationship.
- Case managers are concerned that supported employment providers are using approaches that are not resulting in jobs.
- Case managers are concerned that the Cares Assessment doesn't work well for children and people with less intensive support needs.

- Case managers are concerned that people with disabilities that are not on the waiver will have a real problem accessing services.
- Case managers are concerned that there is a shift from individualized services to a more bureaucratic approach.
- Case managers appreciate the help the County has given regarding PASS/IRWE administration, targeted funding and good data.
- Case managers are concerned that family support is not available to new families.

## Families – Birth to Three

The following summarizes the information from the King County focus group of families with children birth to three with developmental disabilities held in Seattle on November 10, 2004. There were two participants, one father and one mother with children fifteen months and three years of age.

### Themes

The following summarizes the themes from the participants and their responses to each question. Families said they...

- Depend on their Family Resource Coordinator for support and information. Families are concerned about the increase in the caseload of Family Resource Coordinators.
- Are very satisfied with the birth to three services they are receiving.
- Lack information and an understanding of the role of the County in birth to three services.
- Would like to see information available on a County web site that explains how the system works, links to other related web sites, and connects families to other information they need.

### Summary

The participants were very satisfied with the services they received from their birth to three programs. They would like to see more information provided to families on the role of the County.

The participants had concerns about the lack of any centralized way to find information and would like to see a web site that provides them with information and links to sites that could help families.

### Questions and Responses

1. *What is a word or a few words that describe how things are going for young children with developmental disabilities in building skills and helping families?*

In general:

- Family depends on the Family Resource Coordinator for guidance.
- The Family Resource Coordinator is the key link for families.

- When the Family Resource Coordinator has a large caseload the families do not have as much of a connection.

For your child:

- My child is definitely learning, but uncertain about whether she is on target with progress.
- When there is frequent contact with the Family Resource Coordinator it feels like a good connection.
- Parent-to-Parent has been a good connection and a way of getting information.
- Parent support groups have been good and important to family.
- Children's Hospital genetic counselor has been a good resource.
- It would be helpful to families to have a County web site for information rather than having to search for information on services and systems.

2. *Does your child have opportunities to participate in activities with children without disabilities? Are these activities organized by the family and/or agencies?*

- Experimental Education Unit at the University of Washington has an integrated child care program with children with and without disabilities.
- Child attends a generic community dance program available to all children.
- Child attended Samaryi Center, a yoga program for children.
- Child participates in "Music Together" a program for all children.
- PIP program at a Seattle Speech and Hearing Center offers a program for children and their siblings. Siblings are often in a separate class.
- Family uses their church program that is open to all children.
- Family used the Early Parents Support program that met regularly when child was an infant.
- Family participates in social outings connected to disability support groups.

3. *Do you have the supports you need to care for your child and maintain a normal family lifestyle? If not, what would help?*

- Now yes, not before when family lived in California. Things were so intense initially that family sought help through counseling to support each other. There was no respite initially, but found support through:
- Father's group at the Experimental Education Unit at U of W.
- PIP – offered resources.



- Once family moved to Seattle found connections to church and EEU/PIP.
  - Family does not rely on an agency for home support. Family is connected to various support groups, especially the EEU that has support groups that facilitate relationships.
  - Child is medically fragile. It's difficult to find respite and family has concerns about "outsiders" providing care.
  - Families would prefer to go with "known" friends or family rather than formal respite.
  - EEU has "dads'/moms' night out".
  - Talking/networking with other families to share information works.
  - PAVE – parent organization is a good resource (parents are vital in education).
  - Family Resource Coordinator and contact with other families makes a difference.
  - It is a challenge to make all the needed therapy appointments.
4. *Do you feel services for children and families are easy to access and offer choices of services, times and location that meet your needs?*
- Families feel the EEU and PIP do a good job.
  - Families had some choice of service provider.
  - EEU/PIP offers more of a "one-stop-shop" approach, this makes it easier for families, other services/programs tend not to be as convenient and families have to search out programs.
5. *What do you consider the County's "success" in providing you with services that promotes your child's skill development and opportunities to spend time with children without disabilities?*
- Families had multiple choices of agencies.
  - Sibling center at the EEU was a good opportunity for non-disabled child.
  - Family has some concern when non-disabled child might be the only "typical kid" – concern for the non-disabled child.
  - It is hard to know as a parent whether integrated program is always best; but generally feel that it is better.
  - EEU and PIP provide guidance to family on work they can do at home.
6. *Do you know of supports that helped children and families in the past that are slipping away?*

- Families feel they may be too new to know. They have heard about waivers/cuts.
  - Families have not experienced family support.
  - Family Resource Coordinator caseload increasing is a big concern. Higher ratio will take away choice and compromise quality.
  - “Coming to the house” – especially with infants – very helpful with therapies.
  - Respite care for families.
  - Insurance companies – Families need to ask for a “key point of contact.”
7. *If you could wave a wand what would you like to see the county do or change that would help your family and increase inclusion for your child?*
- Web site – some way of organizing information to be more useful.
  - Have a web site where people can share helpful information – this information would need to be monitored and updated.
  - The King County Arc and the King County Parent Coalition are good resources.
  - A way of notifying/alerting families when things change; some kind of automatic response or update.
  - “The County” doesn’t seem accessible. Families lack an understanding or awareness that the County funds birth to three programs, the Arc, King County Parent Coalition and Family Resource Coordinators.

## **Families of School-age Children**

The following summarizes the information from the King County focus group of family members with school-age children with disabilities held in Seattle on November 18, 2004. There were five participants whose sons and daughters ranged from five years old to thirteen years old.

### **Themes**

The following summarizes the themes and lists the participant responses to each question. Parents reported that they...

- Are satisfied with the support their families received. They report that families are having difficulties navigating the various systems as a child grows older and coordinating services from multiple systems. They felt that the County could help facilitate collaboration and communication between parents, programs, and service providers.
- Want to see their sons and daughters have typical experiences, friends, and opportunities to participate equally in community activities. Most acknowledged the value of an integrated experience in school and community activities but some felt that their child made more progress in a setting focused on people with developmental disabilities.
- Feel inclusion was most successful when there was a positive “can do” leadership, from the school principal and structured integrated activities with coaching focused on the strengths of the child.
- Have difficulties getting to various therapy and medical appointments, have a shortage of providers who will accept medical coupons, and experience interagency boundaries and rigid rules in the primary schools.
- Want more funding for transition and supported employment, access to the DDD Voluntary Placement Program, and more funding and flexibility in Family Support.
- Would like the general public to be more aware of the value of high quality services and recognize the people who are doing this work.

### **Summary**

Parents want their sons and daughters to have typical experiences with opportunities to participate in a variety school and community activities and settings.

Parents reported many difficulties receiving support services due to inadequate funding, flexibility and access.

Parents wanted more information about available services and help in navigating services and advocating for their child.

## Questions and Responses

1. *What is a word or a few words that describe how things are going for pre-school and school age children with developmental disabilities to develop skills and help families- in general and for your own child?*

- Bumpy. As children grow and develop, the system responds better in some places than others. You hit bumps as your child moves from one system into another, a little bump if services are readily available and a big bump if you want services that are not available, such as services you want outside of the school district.
- Big bump when parents have to coordinate with various systems, for example, the DSHS Division of Developmental Disabilities and the Mental Health Division, and the schools. It's almost impossible to get all three together at one time.
- I'm worried about parents that don't have the energy or inclination to do the coordination.
- Challenge. Getting up to speed to navigate in a large system, such as the Seattle school system. The transition from the Experimental Education Unit at the UW, an excellent system, has been difficult.
- Self-contained classrooms are not working and lead to problems as students leave school and live in the community.
- Children lose skills over the summer time when they are away from a school program.
- Integrated classes work better at the younger ages than as children get older.
- Integration vs. self-contained classrooms remain an issue. A self-contained program can support better academics, but leads to social isolation.
- Frustration. Feeling torn about giving up support in lieu of inclusion. You have to choose between a person's progress vs. inclusion.
- Inconsistent. Birth-to-three services seemed better organized. EEU is wonderful. Inconsistencies are everywhere in the public school system. It depends on the principal, the teachers, and the building.
- You feel that you have to be a case manager when kids hit school.
- Access to DDD is a complete nightmare for those who are unserved. There are no new openings for unserved families.
- The anti-bullying grant in Seattle public schools may make a difference.
- Integration in the classroom teaches other children about disabilities.

2. *What has worked to promote your child's skill development and relationships with kids without developmental disabilities?*

- When leadership emphasizes inclusion. When the corporate culture, i.e. the school principal, is a leader.
- Contact with other children and have my child grow up with other children.
- Structure and support in integrated activities.
- Programs that focus on the strengths of the child.
- A "supported employment" approach to school classes and activities where kids are "coached" and "supported" to be successful.
- Support for kids to be comfortable in interacting with children with disabilities.
- I'm concerned that social opportunities shrink between the ages of six to eighteen. Kids with disabilities are not generally welcomed into activities. Programs and activities feel that they can't address "special" needs of kids with disabilities.
- Community and city teams and leagues tend not to be welcoming.

3. *Do you have the supports you need to care for your child and maintain a normal family lifestyle? Did you have choices in who would provide support?*

- Respite care is a big deal. Families are in crisis who don't have the support.
- We got great support from DDD to help us negotiate the Individual Education Plan (IEP) with schools. Support at meetings makes a huge difference. Respite service allows needed "time-off".
- Medicaid personal care and family support funding have been good. Finding respite workers has been a challenge. You have to split your time as parents to cover all of the children's needs, such as child care for other children is an ongoing need.
- No. We need support in dealing with the system.
- No. It's very challenging as a newly single parent. Feeling the need to gather all support possible. Medicaid personal care helps, but finding the right person is difficult. The Arc is some of the support.

4. *Do you feel the services for children and families are easily accessible and available at times and location that meet your needs?*

- No. We're constantly driving to therapies and medical appointments. It's inaccessible in terms of location and financial resources. Coupons are being denied. After the child reaches the age of seven, most insurance coverage is denied for therapies which creates a huge gap.
  - No. Issues with interagency boundaries and rigid rules in the primary schools.
  - Competency and skill of a case manager can make a huge difference.
  - Services are available, but not "easily" accessed.
5. *Do you know of supports that have helped preschool and school age children and families in the past that are slipping away?*
- Voluntary placement program in DDD no longer exists for new placements.
  - Family support. New restrictions are limiting use. Flexibility worked better in the past.
  - Ability to have medical coupons accepted due to reimbursement rates. There are fewer providers available.
  - Good programs are at capacity. They won't be available to all that need them.
  - Families are in crisis. Supports are not available.
  - Concern that transition and supported employment might not be available. They are slipping away.
  - Disability services in community colleges need to be supported and expanded.
6. *If you could waive a wand, what would you like the County to do or change that would help your family and increase inclusion for your child?*
- Facilitate collaboration and better communication of all services.
  - Have inclusion become a "way of life", a value that is embraced by all. People with disabilities should have access to the same opportunities throughout their life.
  - Changing the statement from "I don't know how to make this work" to "How can we make this work?"
  - Help to get kids included in regular community activities, teams, clubs, and groups. Help in influencing a culture of community.
7. *Do you have any other thoughts or ideas you'd like to share that haven't been covered yet?*
- People need to be recognized for their efforts. People doing the work should be taken care of.

- Taxes pay for services. This should be emphasized. The County should visibly promote initiatives. High quality services take funding.
- The public should have more education and awareness about the value of services.

## **Families – Transition Age**

The following summarizes the information from the King County focus group of families with transition age kids with developmental disabilities held in Seattle on November 1, 2004. There were six participants, all mothers of children from 13 – 23 years of age.

### **Themes**

The following summarizes some of the themes from the participants' responses and lists their responses to each question. Families said they...

- Are concerned about the ability of the schools to prepare transition students for jobs when they leave school. They said they would like to see person-centered planning for each transition student and would like to see planning start early (middle school).
- Would like to have more information about services and see better coordination between systems (school, DVR, DDD, King County) on behalf of their sons and daughters to make sure students leave school prepared for work.
- Would like to see the County take a leading role in identifying best practices for transition from school to work and work with school districts to implement these practices and to provide training, technical assistance and staff support to schools to increase their competence at job development.
- Are concerned about the isolation experienced by their sons and daughters and would like to see the County involved in creating social opportunities for kids.
- Would like to see the County explore pilot projects that help students be more involved in the community.
- Would like increased employment opportunities. The County should encourage community businesses to participate in hiring students and provide tax incentives. The county should fund a job development position and someone to work with Americorps to develop job opportunities
- Are concerned about the loss of supports that have worked to help students and their families because of funding or policy changes (examples, Community Buddies, flexible family support, community guides, and transition dollars).

### **Summary**

The participants were generally concerned about what will happen to their sons/daughters when they leave school. While they hope that their sons and daughters will have employment, they are not sure if that will happen since there is no guarantee to services for adults after they leave school.

Families would like to see the County provide training and technical assistance to school districts on best practices in the area of transition. They would also like to see the County take a more active role in promoting social opportunities for young people with disabilities. Families are concerned about the isolation of their sons/daughter isolation and lack of friends.

## Questions and Responses

### *1. What is a word or a few words that describes how things are going for young people with developmental disabilities in school transition?*

- Frustration from families:
- Waited to long to think, plan and prepare for my child's transition from school to adult services.
- Would like son to graduate with a job, but not sure if he is employable.
- Schools are not thinking about transition at age fourteen.
- Age 21 is a big shock – Families are used to entitlement and are not prepared for adult system with no guarantee.
  
- Frustration regarding the adult service system:
- Families don't understand the adult system or the players in that system.
- Parents often do not have a vision of employment for son/daughter.
- Boundaries at agencies are so artificial and difficult to understand.
  
- Frustration with school system:
  - There are inconsistencies in the types of services and information that families get from school district to school district.
  - Schools want to graduate students at eighteen which makes them ineligible for additional transition services from the school.
  - Schools are not doing comprehensive transition planning with students and their family.
  - There needs to be more assistance for families to advocate for transition services within the school system.
  - Schools are not identifying mental health issues for students with developmental disabilities.
  - There needs to be more partnerships and planning for students by schools and adult service systems (DVR, DDD, Mental Health and King County).
  - Lack of support from schools for jobs in the community - Not enough aides to help with job training and support.
  - Kids that have jobs have no support in the summer when school is out.
  - Lack of creativity – Schools need to be looking for best practices on supporting students to have jobs.
  - Families need to push teachers that would prefer to just baby sit students.
  - Schools need to rethink their roles and responsibilities to meet the needs of transition students.
  
- It is good that DVR will sit in on planning at age fourteen.



- SEAAC does share information on transition between districts.
- Parents need to participate and be responsible – Give back not just get a hand out.
- Parents feel overwhelmed:
  - Who do you go to for information on adult services?
  - Why is there no cross referencing of information between service systems?
  - DVR seems out of touch with resources and are not experienced in working with students with developmental disabilities.
  - Why isn't everyone working together on behalf of these students?
- Scared – Lots of things going away at twenty-one.
  - Afraid of the unknown. What will happen to my kid when school is done?
- Why can't we start with what you want for your kids and then have the system help families get there?

2. *How would you describe your son/daughters readiness to enter the workforce and live independent?*

- Family has been working with teacher on future employment – Maybe start own business.
- Son went part time into transition program and eased into a job.
- Not ready – We are all too protective.
- Mother has always been preparing him.
- The family is working on a plan and has high hopes that son will have a job.
- Employment training needs to be reinforced at home.
- Son is ready to work.
- Family will have a difficult time affording daughter's independent living.
- Mother wants son to have his own place and has been planning this for years.

3. *Do you have the support you need to care for your son/daughter?*

- No – Family feels like there are no options for daughter residentially or employment.
- Support falls to the family.
- Family would like to have more competent staff – Medicaid Personal Care.
- Need more community resources – There is too much isolation for people with disabilities.

- Wages are too low for support staff (e.g. Medicaid Personal Care). Families have to supplement cost of support.
  - Sons/daughters have to rely on family and family networks.
4. *Do you feel services for young people and their families are easily accessible and do you have choices in services, times and location?*
- Services are difficult to access. Don't even know what to ask for.
  - DDD doesn't allow you to be creative with the money.
  - Not enough resources – difficult to get involved in generic community for fun and friendships.
  - Families with the greatest need usually get the least amount of help.
  - Policies and procedures make choice impossible.
    - Family had dollars available through DDD and wanted to build a ramp for wheelchair – DDD said no, had to use family dollars to build a ramp.
5. *What has worked well to promote your son/daughters opportunities for friendships?*
- Stepping out for Fun Program
  - Need more social skills training in school so kids can recreate.
  - Father created a boy scouts troop that does a lot.
  - Inclusive, typical activities almost non-existent.
  - Son has lots of opportunities to have friends but no support to encourage and maintain friendships.
  - Children's Hospital offers social skills group.
  - Ski For All.
6. *Do you know of supports that helped young people be included in the community that you see slipping away?*
- Community Buddies – pair kids with disabilities with kids without disabilities
  - Pilot programs are often successful but funding doesn't get continued
  - Flexible family support no longer available.
  - Community Guides through DDD not the way it used to be.

- Transition dollars not available anymore
- .
- Voluntary foster care program.
- If you could wave a wand what would you like to see the County do that would help young people transition from school to work?
- Technical support to schools to help students transition to work :
  - Teach teachers how to prepare students for real work.
  - Help students with financial planning for their future.
  - Train employment vendors on how to support students on the job.
- Make sure every student has a person-centered plan that has goals for employment.
- Provide wrap around services for students to identify all their needs
- .
- County should connect with OSPI to help them figure out what to do for kids
- .
- Advocate for transition dollars for every transition student.
- County should partner with school to have someone paid to do community outreach for jobs.
- Look at senior service model of training people to answer phones and do other jobs as assessment sites.
- Teacher/Student ratio needs to decrease if students are to be adequately prepared for jobs.
- County needs to import best practices for transition and work with schools on implementing these practices
- County could work with community businesses to hire students with developmental disabilities and receive tax incentives.
- County could fund pilot projects that match transition students with Americore staff to provide after school places for students to go and provide vocational training at businesses.
- Parents need to volunteer and use their connections to find job opportunities.

## **Families of Working Age Adults**

The following summarizes the information from the King County focus group of families of working age adults held in Seattle on October 21, 2004. There were five participants, all mothers of people with disabilities who are working age.

### **Themes**

The following summarize themes from the session and participants' responses to each question. Families...

- Are generally satisfied with the employment services their sons and daughters are receiving, but would like their sons/daughters to have more choices of jobs and opportunities for advancement.
- Need more information on available services and responsible agencies.
- Spoke about difficulties working with systems to get what they need, specifically getting through the eligibility process and obtaining services that meet their needs.
- Want more transition services and funding in the schools, counseling, and independent living support.
- Strongly supported the need for job coaches and "follow-along" services.
- Have serious concerns with the DSHS Cares Assessment Tool. They believe that the assessment is subjective, disrespectful, legalistic, and only represents a "snap shot". They believe it results in a reduction in the hours of support.
- Are concerned about frequent case management and residential program staff changes.
- Want their sons and daughters to have more opportunities to participate in and contribute to community life.

### **Summary**

The participants were generally satisfied with the services provided by the County. They supported more employment options, more information about systems, and more funding for transition, education, and other state-funded supports.

The participants had concerns that the Cares Assessment Tool was not a good determinant of a person's support needs and seemed to have the effect of reducing levels of support.

Parents want their sons and daughters to have more opportunities to participate in community activities.

## Questions and Responses

1. *What is a word or words that describe how you think things are going for adults with developmental disabilities?*

- Very happy with the employment vendor.
- Okay until 6 months ago (with the Cares Assessment). Wading through the system is difficult (e.g. getting good information, understanding eligibility rules).
- Constant struggle. People really have to fight for DD services.
- Lots of people with neurological challenges don't qualify – Some are being disqualified.
- Cares Assessment tool is awful. It doesn't capture a real picture of people, but just how they seem on that day.
- Parents don't know about the resources that are available and how to get them.
- Pretty good right now. Son has done well since he got a job coach.
- Co-workers and supervisors have been great.
- Son could not have gotten the job on his own.
- Criteria for transition arbitrary. Varies according to school district.
- "The system" is frightening, intimidating, very difficult to get through.
- Son doing well, but it was very difficult to get information on services.
- Recent review using Cares tool we were told to make sure it was on his worse day so he would more likely receive service.
- Difficulty finding information on services and resources. How do families get information?
- Case manager couldn't answer questions.
- Lots of people losing service because of new tool.
- Other than employment agency staff there are no consistent staff people.
- Assessment very problematic – Very legalistic, very subjective and depends on case manager.

2. *How would you describe your family member's opportunities to obtain and keep a typical job and live independently?*

- Our daughter couldn't keep job without job coach.
- Providing and advocating for services takes a lot of work. Families need to be involved.
- Son is successful because of job training and the follow along with the job coach.
- People need to have more choices of jobs.
- Daughter lives at home with parents. Independent living right now is scary.
- Father was job coach for awhile.
- Assessment – If you have a low score you don't have to retest.
- Apartment – feels like a parent cannot move away.

3. *Does your son/daughter have choices of services that match their interest and needs?*

- No – There is a lack of stable staff with their residential provider.
- Choices are limited but are probably as good as it is going to get. Daughter is difficult to support because of her physical disabilities.
- Pretty good choices but not residentially.
- It seems that the choices have little to do with a person's interests or needs.
- No – not a lot of employment choices.
- Few choices. There are scary living situations offered to people.

4. *What are the County's successes in promoting your family members relationships, work and independent living?*

- The County staff's networking led to finding a successful vendor.
- The County's use of consultants has been very successful, such as training and positive behavior support.
- The County has been successful in hiring people with disabilities.
- DVR and DDD workers are hardworking.
- Staff have been successful doing benefit analysis.
- Residential supports are not adequate.

- Support from the County to help people move from sheltered to community jobs.

5. *What worked in the past that you see slipping away?*

- Transition services and the money for transition students were better in the past.
- Schools are not preparing kids for world of work as well as they have.
- Hours of support have been dramatically cut through the Cares assessment.
- Parents have to remain at home to support sons/daughters due to cut in hours.
- Sufficient service hours and funds have to be there to promote inclusion.
- There is no planning since Cares Assessment.
- There are fewer opportunities for promotions in jobs since agencies don't have enough money for staff to help people advance.

6. *Are there areas of County support of adults that are not going well and need improvement?*

- County officials should spend one weekend with kids to understand how difficult it is for families and to have an idea of who people are and what they need.
- People need more counseling services and independent living services.
- Care Assessment Tool is subjective and demeans people through disrespectful questions. Questions should be asked in ways that can be easily understood by person and family.

7. *If you could wave a wand, what would you like the County to change regarding inclusion for adults?*

- All people that need a job would have one.
- More dollars would be available for job coaches.
- People would have good wages and get promotions.
- Have the dollars they need without the demeaning assessment tool.
- Agencies involved with a person would cooperate with one another.
- People would be accepted for who they are and be valued individuals.

- Families could help their sons and daughters grow rather than spend so much time just taking care of issues.
- People would be treated like everyone else – with more respect and dignity.

8. *Do you have any other thoughts or ideas you'd like to share that haven't been covered yet?*

- Parents should get information on what services are available and the services that are actually delivered.
- Medical coupons don't provide a quality choice.
- People should have more opportunities for social interactions with a variety of people.
- Personal safety is a huge concern of parents.
- Transportation needs to be flexible.
- The County needs to be more supportive of contracted employees.



## **Older Families of Adults**

The following summarizes the information from the King County focus group of older families of adults with developmental disabilities held in Seattle on October 25, 2004. There were five participants, four mothers and one father of adults with developmental disabilities.

### **Themes**

The following summarizes themes from the session and participant responses to each question.

- The participants are happy with the quality of County support for employment services and funding for the King County Parent Coalition.
- Families want more information on the service system and resources.
- Families want to see their sons/daughters have jobs.
- While some families acknowledged receiving adequate services, others felt that assessment and resource allocation decisions do not meet their needs.
- Families would like to see their sons and daughters have more friends and social opportunities, separate from the family.
- Parents are worried about the safety and well being of their sons and daughters if they are no longer able to care for them.
- Families are concerned about the lack of housing options and reliable transportation.

### **Summary**

The participants were generally satisfied with the services provided by the County but are concerned that other support services are not adequate to meet their needs. They want more information about how the system works and available resources.

They want more opportunities for their sons and daughters to have friends, access to reliable transportation and housing options. The participants were worried about the safety and well being of their sons/daughters when they are no longer able to provide support.

### **Questions and Responses**

1. *What is a word or a few words that describes how things are going for adults with developmental disabilities? (Both generally as well as specifically related to your family member)*

In General

- Case managers take a long time fulfilling needs/requests.
- Things are better but there are still not enough services for people.
- Families fear for the future – who will care for their sons/daughters when parents can't?
- Shifting resources have created “haves and have-nots”.
- Day-time activities for people are necessary.
- Politicians make promises but don't live up to them.
- The language used by professionals and service providers is difficult to understand – too complicated.
- Parents need to have places where parents can come together.

**For Your Family Member**

- We have to wait a long time for everything.
  - My family member has no day program.
  - Who will understand my son when I'm no longer around?
  - Our son does not have friends.
  - Our family member depends on parents to get around.
  - The guardianship process is disrespectful, punitive and inflexible.
  - I did not know about how to access mental health services for my family member.
  - Medication problems – no educator to help figure things out.
  - We need someone to help and teach parents.
  - There is a lack of support and information.
  - Families fear there will be retaliation against their sons/daughters if they complain about services.
2. *How would you describe your family member's opportunities to have relationships and meaningful activities in the community?*
- None. Our son is isolated and has no friends.

- The Cares assessment does not reflect an individual's needs.
  - My daughter enjoys doing yoga once a week.
  - Resources are difficult to find – often parents find them by accident.
  - Information on services and resources is not readily available.
  - Support needs are much greater than the resources available.
  - People with disabilities need to have peer friendships.
  - Schools do not have information for families on resources and service options.
  - Case management does not provide information.
  - Staff change too frequently and they do not have a chance to get to know people.
3. *Are there barriers that interfere with your family member's opportunities to be more involved in the community?*
- The presence of food at gatherings is a problem for my son. Social activities focus on food. His disability limits his job opportunities.
  - Behavior issues interfere.
  - Transportation services. Getting out of the house in general is difficult.
  - Parents have safety concerns.
  - Parents worry about the exploitation of people who are vulnerable.
  - People need support to engage in social activities.
  - There is a lack of jobs designed for people with disabilities.
  - People are excluded from jobs because of perceptions about their behaviors.
  - I don't trust that individuals will get the support they need.
4. *What do you consider the County's "successes" in promoting your family member's opportunities to be involved in the community through work, relationships, other activities?*
- Creating the King County Parent Coalition.
  - Ray Jensen & staff really support families.
  - The County takes a leadership role in employment for people with disabilities.

- The County is not rigid on services.
- The County's work with Involving All Neighbors.
- The Counties role in expanding housing opportunities.
- The County creating the opportunity for families to provide input.
- High quality employment services.

5. *Do you feel services are easily accessible?*

- Yes, there are more things available in the Shoreline area.
- Yes, but you have to stay informed. Services are not accessible for much of the general public.
- Families have to continually update their information on resources.
- Anytime money is provided case managers keep people in the dark to save money.
- Recommend that the system provides families access to an information broker.
- Vocational rehabilitation services are difficult to access.
- You have to know who to call and which words to use to get what you want.
- Parents need to know what questions to ask.
- The language of the system itself is a barrier.

6. *Does your family member have choices in the type of services, providers, hours and location that match their need?*

- No – we have no County services.
- Our choices are very limited.
- Our family has some good options.
- Northwest Center has been the only option for our son.
- There needs to be more choices in a person's own geographic area.
- We have choices, but do not have the transportation support to access them.

7. *If you could wave a wand what would you like the County to do that would increase opportunities for inclusion in the community?*

- Provide more money.
- Promote more activities for people that do not rely on the family – families need a rest.
- The County should provide trusted and reliable transportation.
- We need someone to be there when we call – someone to come and give us a break.
- The County should continue to work with housing.
- People need more individual planning opportunities.
- Parents need to be able to come together to teach each other and share what really works.
- We need to educate the public about disabilities.
- I think its okay to congregate people under certain circumstances.
- The County should have information brokers.
- We need more and better low cost housing.
- Families need access to people who are really trained to provide respite.
- We need quality care when the mother is incapacitated.

8. *Do you have any other thoughts or ideas you'd like to share that haven't been covered yet?*

- Case managers need to be better trained and care more about people and their job.
- Families need information and training on what's working elsewhere.

## **Residential Services Providers**

The following summarizes the information from the King County/DDD focus group of residential providers held in Seattle on October 25, 2004. There were four participants, providing residential services in King County.

### **Themes**

The following summarize themes from the session and participant responses to each question. Residential providers...

- Believe there are too many people that are unemployed and spend too much time at home, particularly people with more significant disabilities.
- Would like to see more communication and collaboration between state, county and providers.
- Are concerned that the system's focus on quantity rather than quality is undermining power and choice for people with disabilities.
- Are concerned about the centralization of decision making in the Department of Social and Health Services that results in less local flexibility to meet individual needs.
- Believe that there are more regulations not related to quality and it detracts from their ability to provide high quality support to the individual.
- Want to see the system focus more on instituting "best practices".
- Want more opportunities for staff training and development.
- Would like to see people with disabilities have more control over their lives, and person-centered planning, support services, provider and funding options.
- Want people to have more opportunities for social integration and interdependent rather than dependent relationships

### **Summary**

Residential providers supported more training, communication and collaboration between providers, the county and the state.

They wanted to see people with disabilities have more control of their lives and more opportunities for social integration.

Providers were concerned about increased “centralization” of decision making that has resulted in less flexibility to meet peoples’ needs.

Providers wanted to see more people employed specifically people with significant disabilities.

#### Questions and Responses

*1. What is a word or a few words that describe how things are going for adults with developmental disabilities to live independent?*

- It is more difficult now for people to have a regular life than it used to be.
- The service system, specifically residential service, is less flexible, less risk taking, and more regulated.
- There is less tolerance in society for unusual behavior. People need to have a positive behavioral support plan at the drop of a hat.
- People are still treated or acted upon as inanimate objects – addressed as the problem.
- It often feels like we are regressing. Too much value being put on how people should live.
- Division has put firewalls up that limit power and choice. Still holds the strings on things that should be within the control of the individual.
- The system is challenging.
- Helping individuals to lead interdependent lives, rather than dependent lives, can lead to more safety.
- Life in general is faster paced than in the past.
- Living independently depends on whether you are in or out of services. There are too many people who are waiting for services and support.
- The system is precarious.
  - People are isolated and lonely.
  - Jobs – People don’t have them – especially people with greater support needs.
  - Not as much learning going on. Far less than in the past. There is no emphasis on staff and service development.
  - The county and the state are not communicating resulting in people not getting to develop in ways they really want.
- The system is more centralized in Olympia – Local relationships among agency and providers are being devalued.
- There should be a lot more communication with one another.

- There is great disparity in services that are available to people.
  - Employment services are not readily available. There should be other provider options – People are sitting home – there are not enough employment resources.
2. *What has worked well in promoting peoples' ability to live independent?*
- Person-centered planning with individual leading the process.
  - Getting out of people's way.
  - Helping people take control of their lives.
  - Embracing the process of change at all levels is not as present as it used to be.
  - Stakeholder process was the beginning of a downward slide in how it is valued and communicated with stakeholders, service providers and state and county agencies.
  - Services help most when people get individualized support.
    - Residential service decisions shouldn't be driven by funding – it results in more congregation.
    - The system needs to be more fluid. People should be able to move if they want to.
  - Having consistent committed staff who are optimistic.
  - Having fewer boundaries between residential and employment staff.
  - Having greater family involvement - more interactions.
3. *Do you know of supports that have helped achieve inclusion for adults in the past that are slipping away?*
- There is more emphasis on people having activities rather than inclusion.
  - There used to be more opportunities for one person to go out with one other person, rather than with groups of other people receiving services.
  - The employment system.
    - People are at home that used to be working.
    - Employment providers focus too much on a person's negative attributes. They screen out people if they seem difficult and are not thinking about innovative supports. They "hand pick" people most likely to succeed on the job.
  - You can't count on people having things to do outside of their home especially people with greater support needs.
  - What is deemed to be appropriate funding is a fantasy. The service system must have an incentive for serving people who are harder to serve.
  - There is no emphasis on best practices.



- The requests and requirements under “indirect” service have dramatically increased. The result of this is having less direct time with people and people can’t do the things they want to do.
  - When we are short of support time, we provide more physical integration rather than social integration.
  - The system promotes defensive practices instead of proactive support. This is less freedom for people to do what they want.
4. *Are there areas of support for adults to live independent that are not going well and need improvement?*
- We have never really sat down and asked “What’s it going to take to support people with more significant challenges?”
  - For many people supported employment is not that different than sheltered employment.
  - The system has never delivered on the promise to get everyone a job or educational opportunities.
  - Residential service providers should be able to provide employment services, especially when employment providers are unable to help a person get a job.
  - The system needs to develop new employment providers to give people more choice.
  - Development of new providers hasn’t happened in a long time.
  - There needs to be a better variety and quality of mental health and substance abuse providers.
  - Transportation services. Residential providers do not have the staff to transport people where they need or want to go.
  - There is a lack of consistency and coordination between employment and residential services.
  - Staff do not know as much about teaching people as they have in the past.
  - Natural supports don’t always work and job falls apart.
  - Years ago, you were a collaborator with state & county. There is a mind set change – state and county spend time putting out fires rather than supporting vendors. Providers would like to have a real partnership.
  - There is a focus on the quantity of service over quality of service.
  - There used to be more emphasis on staff training and conferences.
5. *If you could wave a wand what would you like to see the County change to better promote inclusion for adults?*

- County must make every effort to fund quality employment services.
  - Change the way in which employment services are funded.
  - More flexibility in support and training.
  - More creativity.
  - Get away from physical inclusion toward more social inclusion.
  - Invest in people with disabilities. There needs to be more exposure of people with disabilities to their communities through education and information. The public doesn't have much exposure to people with disabilities.
  - People with disabilities should be able to choose their provider rather than providers choosing individuals.
  - The County should set some goals in terms of serving people with more support needs.
  - The County should front load their funding so that people can be adequately supported early in their job when they need support.
  - The State has really moved away from funding local services and programs and toward large centralized services and programs.
  - The County must provide more options for planning and support.
  - We should not find one way to do things and then rest on our laurels.
6. *Do you have any other thoughts or ideas you'd like to share that haven't been covered yet?*
- The County doesn't have a variety of staff who can answer complaints – can't always go to Ray.
  - Case managers often don't even know who provides employment services.
  - The County should be praised for its work on Section 8 Housing.
  - There should be a document available to the public on where the County spends its money and why.

## Birth to Three Providers

The following summarizes the information from the King County/DDD Focus group of providers of services to young children held in Seattle on November 18, 2004. There were seven participants, providers of early intervention services, child care providers, and child care resource and referral agencies.

### Themes

The following summarizes the themes from the session and participant responses to each question.

#### Birth to Three Providers...

- Felt that child-care and early intervention services were doing well although there are gaps in some services, such as child-care, respite, family support, transportation in some isolated geographic areas and interpreter services in some communities where language can be a barrier.
- Want to work more collaboratively with the County and have more flexibility in providing services, for example coordinating child-care services between two counties.
- Urged more funding for child-care, language interpreters, and staff training. They said that vendor rates have not kept up with cost increases.
- Were especially concerned about the reduction in the funding and flexibility of family support services.
- Generally agreed that the relationship with the County needed to be improved. They described often “adversarial” relationships, a lack of trust, and “disconnects” in monitoring, policy, and program administration.
- Acknowledged where the partnership with the County worked well. They spoke positively about information sharing, advocacy, and support for simplifying billing processes.

### Summary

The participants felt that services in most areas with most families was going well, although they acknowledged gaps in access to some services in some geographic areas.

Participants urged greater funding and flexibility in some services such as child-care, family support, and transportation and greater financial support for child-care and vendor payments.

Participants wanted a more collaborative and positive partnership with the County.

## Questions and Responses

1. *What is a word or a few words that describe how things are going for young children with developmental disabilities to improve their skills and to meet the needs of their family?*

- Going well. There are numerous competent services that are easily accessible.
- For child-care, there are gaps in the training of staff in best practices and their knowledge of resources.
- Inconsistent. Some families are receiving good services and some are getting little or none. Families that are connected to local resources and supports and network well do better than families who are isolated.
- Going well. There is tremendous variety and opportunity. There is some concern for families where both parents work and single parents who have less flexibility to access services.
- Early Intervention Services are very good. Services are better than they were 10-15 years ago. King County compares favorably to other counties in the state and Washington compares favorably to other states.
- People who live in geographically isolated areas still experience access problems. Culture and language barriers still present a challenge in accessing services.
- Early Intervention Services are going very well with qualified and competent providers and many choices for parents.
- Child-care and respite care is still an area of need. Providers often receive calls from parents regarding children who are not able to get service because of their disability.

2. *Are there areas of County support for young children and their families that are not going well and need to be improved?*

- Reaching families in geographically isolated areas of the county, such as in Skykomish and in the southeast. Census data can be misleading in areas that appear under-served.
- Providers work together through the medical centers and the schools to assure that kids are not being missed. There are good referrals for early intervention coming from the medical community across the County.

- There are universal inadequacies in day care for all kids.
  - Behavioral issues seem to be the primary reason that children with disabilities are screened out by providers or expelled from daycare.
  - Providers are faced with issues involving more complex care and the additional time it requires of caregiver in day-care. There is no financial incentive to support taking kids.
  - County financial support is lacking
  - The relationship between the County and providers needs to be improved:
  - There are disconnects between the program side of the County, the monitoring side, and administration. Examples are; confusion about billing and getting different messages from program management, monitoring, and administrative staff about center-based or community-based services.
  - The relationship seems adversarial much of the time and has for a number of years.
  - High turnover of County staff has made it difficult.
  - Has not felt like we are working together to address needs of children.
  - The relationship with the County is fragmented, burdensome and takes away, rather than adds, value. For example, program evaluation reports are delayed (e.g. four months after the evaluation) and don't support the verbal feedback at the end of the evaluation.
  - The evaluations are inaccurate, delayed and overbearing. Overbearing in that the County evaluators do not have expertise or knowledge and display a lack of respect.
  - County staff apply global solutions to very specific issues or situations. The result is policy based on issues that may not reflect all of the funding streams that must be honored
  - The County tends to pull and want control without consideration of others.
  - There are changing rules on covered services and changing funding.
3. *How would you describe the opportunities for young children with disabilities and their families to participate in activities with children without developmental disabilities?*
- There are good opportunities. The majority of families spend time in activities that are generic. Examples are girl scouts, church activities, kids chorus, kids theatre. There is a feeling that this decreases as the child starts school.
  - The focus of the Individual Family Support Plan is to support the child being included in other opportunities.
  - The lack of child-care providers leads to some kids being more isolated and cared for in more isolated settings.
  - There is a lack of financial support to provide a level of care that is necessary.

- Providers try to help families connect to generic resources and activities. It might be difficult for some parents to sort through all of the resources. It's overwhelming to some parents.
  - Parents need to advocate for more opportunities. Providers are trying to help.
  - There are opportunities but access can be a challenge (e.g. isolated areas, little transportation, working parents, etc.).
4. *What do you consider the County's "successes" in promoting inclusion and support to families?*
- Providing County funding for disability specific training (e.g. training for staff regarding autism). After training, staff were able to share information with families and saw changes in the opportunities for children. The training was good and process was good.
  - County funding to train child-care staff is very helpful but more is needed.
  - The County is successful in partnering with community groups to expand inclusion.
  - Getting information regularly from the County and meetings between the County and providers.
  - The County was successful in simplifying the billing process. It is getting better after several years.
  - The County was supportive and an advocate for the providers adjusting to a new state data system. The data is more functional now.
5. *Do you know of supports that have helped children and families in the past that are slipping away?*
- Family support is the biggest slip, specifically:
    - Families now need to be in an emergency situation for services.
    - Very few families have access.
    - The flexibility in how families use the funds is gone.
  - There used to be more parks and community programs designed to specifically meet the needs of children with disabilities.
  - It's harder now to "share services" and work collaboratively, though this is not necessarily the fault of County. Child-care rules and a "managed care approach" make it more difficult to make natural connections between providers.
  - Serving families "between counties" (e.g. a family that lives in one county and works in another) used to be more manageable and is now almost impossible due to different access rules.
  - Funding for enhanced child-care resource and referral no longer exists.

- Funding for and access to language interpreters. It can be very difficult to find an interpreter.
- There used to be more funding for interpreting and funding to train staff on cultural issues.
- Vendor payments have slipped in dollar value because:
- Increasing administrative responsibilities, mostly from the state, that do not add value to the program.
- Vendor rates have not kept up with inflation.
- Enrollment growth.
- King County, however, has allowed payment for each child, which is not true in every county.
- The level of trust between the County and the providers is at a low level.

6. *If you could waive a wand, what would you like the County to do or change that would help families and increase inclusion for children with developmental disabilities?*

- Eliminate the “parallel” system with the County and the state programs. Collapse the two systems and pass the administrative savings to providers.
- Better transitions between services for children as they age and more collaboration and connections between programs.
- Enhanced or additional child-care subsidy to make it easier for families of children with disabilities to get served. An example would be an add-on to the state subsidy like the City of Seattle provides.
- Better reimbursement for home, child-care and community visits by provider staff.
- Better transportation for families. Families have a hard time getting to services or activities.
- Need better bus routes.
- Access rules regarding the age of the eligible child (under 6) are not flexible to allow other families members to ride along.
- The County would understand that they are a “piece” of the system, but they can’t control the service.

7. *Do you have any other thoughts or ideas you’d like to share that haven’t been covered yet?*

- Reduce administration at the County. More County staff add administrative burden to providers.
- Would like to see families have more control of choices in adult life. Some choices have been removed. Hope that sheltered workshops and enclaves would still be options.
- Would like more opportunities to know what’s happening in the adult service system. There used to be more opportunities such as shared conferences.

- Would like more early childhood representation on the County Board. There used to be service committees that was more effective. There is not much opportunity to address early childhood issues.
- There should be more communication about training and conferences that would be appropriate for staff, families, and child-care providers.

## Community Access Providers

The following summarizes the information from the King County focus group of providers of community access services for adults with developmental disabilities held in Seattle on November 23, 2004. There were four participants, all serving adults with developmental disabilities.

### Themes

The following summarizes the themes from the session and lists the participant responses to each question. Providers are concerned about...

- Their ability to continue providing services with the rate they are being paid. They are especially concerned about the future of people with the most significant disabilities due to the rate.
- Their ability to cover necessary training costs without the County paying for the staff to attend training sessions.
- The reduction in financial resources as well as rigidity in rules.
- The loss of opportunities to be creative due to new waivers and policies.
- The lack of communication between systems to try to deal with issues.
- The County's interpretation of the policy for working age adults will result in the loss of quality, values, and individualized planning and services for people with developmental disabilities.
- The momentum toward serving people in groups rather than individualized supports.
- The lack of support for person-to-person services that has allowed for meaningful planning and time to work with people with the most significant disabilities.
- The growing waiting lists and lack of resources to address the list.

### Summary



The participants were concerned about their ability to continue to provide services to individuals with significant disabilities.

Participants generally believe the integrity and values of individualization are being replaced by a push toward group activities due to insufficient rates and rigid policies.

Participants are also concerned that they can't afford to send staff for critical trainings to build their skills and competence due to loss of the daily rate while staff attend training session.

Participants felt the new waivers and policies have reduced their capacity to provide services and limited their ability to find creative solutions. Participants would like to see the County facilitate communication between systems to address these issues and concerns.

## Questions and Responses

1. *What is a word or a few words that describes how things are going for adults with developmental disabilities to pursue community activities and employment goals?*
  - Moving slowly; but encouraging because it seems that it will happen. The new employment policy has provided a focus on making it happen. Provider felt it is now more than just the agency pushing for employment, but rather a policy that clarifies the direction.
  - Picking-up speed. The change in rules (eligibility for skilled nursing and rehabilitation) made it more difficult to offer services that increase socialization for a period of time. The agency is now receiving more referrals and families are more knowledgeable about how to describe services to obtain eligibility.
  - Progress – People with more significant disabilities have had a longer pathway to employment that allows for “contribution” to be valued. This has led to slow progress.
  - Resource Poor – People have to fit in a waiver box - limited resources and rigid rules diminish creativity.
  - Breakdown of partnerships between county, state and providers. Participant feels discouraged and devalued. Also concerned about:
    - Diminished resources
    - Diminished flexibility
    - Unrealistic expectations
  - Misunderstanding of Working Age Adults policy – Participant would like to see a less rigid interpretation of policy.
  - Wrong, Wrong – Participant feels that group settings are being encouraged for community access rather than individualized - Not like this before new waivers and policies.
2. *What do you consider the County's successes in promoting inclusion for adults with developmental disabilities?*

- Leadership in supported employment – Participant hopes that the push to expand corporate employers continues.
  - Opportunity to individualize and be creative, but it feels like this is going away.
  - Vision that people will get to employment.
  - County’s acceptance that “pathway” may be a long path.
3. *Do you know of supports from the County that have helped people achieve inclusion in the past that are slipping away?*
- Person-to-Person – A resource that has allowed time needed to plan and develop services for individuals.
  - Individualized support – Resources are decreasing and people are being pushed into group situations.
  - The opportunity to consider each person’s unique gifts and work from there – This is slipping away.
  - Feeling forced to move people with more significant disabilities to a place of less priority/value.
  - Values are slipping away.
  - The choice of integration of seniors into integrated senior services may be eliminated due to lack of resources – forcing seniors into segregated adult day care.
  - Most discouraging point in last 20 years of providing services.
4. *Are there areas of support for adults with developmental disabilities that are not going well and need improvement?*
- Community access needs support, value and resources.
  - Case Management needs to have lower caseloads and expand awareness.
  - Partnerships/Trust/Collaboration
    - Complete breakdown between systems.
    - Waiver interpretation is rigid and does not need to be,
    - Providers and people with disabilities feel caught between the County and state power struggle.
5. *If you could wave a wand what would you like to see the County do or change that would improve integration and services for adults with developmental disabilities?*
- Support each person in service as an individual, not going back to people being put into rigid boxes.

- Promote opportunities for people with various perspectives to come together and mend system issues.
- Provide more money or give flexibility to be creative or both.
- Honor commitments that have been made to those people downsized from residential habilitation centers and sheltered workshops. People have verbal and written commitments and these commitments need to be honored.
- Address the issue of resources being cut while the waiting list for services is growing.
- Parents “wants” tend to fall into two categories (Those wants are quickly coming to a crisis level).
  - They would like employment, career path and inclusion for their sons/daughters.
  - They want respite, particularly during the day.
- Training and Technical Assistance:
  - Values training for staff.
  - Information for families on rules, policy changes; waiver training. Start this training at an early age; parents need to be aware there is a cap on funding which results in a cap on services.
  - Basic training – High staff turnover – Need values training; job development; support skills, etc.
  - There is a disincentive to send staff to training – takes away from daily rate and agencies can’t afford to send staff. Agencies need an administrative rate included in reimbursement.
- Hourly rate does not cover program costs – Agencies have to rely on other programs like the Division of Vocation Rehabilitation to float Community Access. County needs to pay for Community Access costs.
- More seed money for generic community services like North Shore Senior Services – Good investment.
- Counties are interpreting work age adults policy differently. Snohomish County seems to have been able to maintain the integrity of services in spite of the waiver. Counties need to work together to share information on what they are doing to help all counties maintain the integrity of the services.
- Agencies must be able to build and maintain staff skills and needs the County to cover staff hours so that programs can afford to send staff for critical training events.
- County needs to fund “start-up” for small business ventures for people with significant disabilities.
- Keep up and expend development of public sector and larger corporate employers. Expand those efforts into areas outside Seattle like Bellevue, Shoreline, Burien, etc.

## Employment Providers

The following summarizes the information from the King County/DDD Focus group of vendors of individual employment services for adults with developmental disabilities held in Seattle on November 29, 2004. There were ten participants, all serving adults with developmental disabilities.

### Themes

The following summarizes the themes from the session and participant responses to each question. Vendors are...

- Pleased with the County for its leadership, valuing full time quality employment, educating the legislature, supporting training and technical assistance, and promoting employment of people at the County.
- Concerned about their ability to provide services without the flexibility of block grant funding.
- Concerned about the lack of information being shared with them on new contact requirements and their impact on people with developmental disabilities.
- Concerned about their ability to cover necessary training costs for their staff.
- Concerned about the reduction in financial resources, the rigid interpretation of rules and the loss of flexibility due to new waivers and policies.
- Concerned about the future of people with the most significant disabilities due to the reimbursement rate and policies.
- Want the relationship and communication with the County to improve.
- Are concerned about the loss of emphasis on quality and values.

### Summary

The vendors have a lot of trust in King County Developmental Disabilities and respect the leadership that King County has provided over the last 20+ years. They are proud to be recognized nationally as employment leaders.

Vendors are concerned about the lack of information being shared with them on changes they expect to see in their contracts beginning January, 2005 and the impact these changes may have on the people with developmental disabilities they support, in particular people with the most significant disabilities.

The vendors believe that block funding has enabled them to provide quality services and see this flexibility going away. Participants are concerned that the integrity, values and outcomes of supported employment are in jeopardy due to the waiver requirements and other policy changes as well as the County's interpretation of the requirements.

Participants felt the new waivers and policies have reduced their capacity to provide services and limited their ability to find creative solutions.

Participants would like to see the County facilitate communication between local parties to address these issues and concerns.

## Questions and Responses

### *1. What is a word or a few words that describes how things are going for adults with developmental disabilities to pursue employment goals?*

- Moving slowly - The process of getting people employed is taking longer because of the economy.
- Losing choices - People with disabilities lives are being affected in all areas. They are losing choices in where they live and what they do during the day.
- Progress is stalled – For many years, the system was steadily improving and providing people with more opportunities. The new policies, waivers, and Cares planning process are unclear and creating confusion and concern about where the system is going.
- Moving backward in all areas, independence, residential, schools, etc.
- Confusing – Families don't know where to go for help. The rules for systems are unclear.
- Scarcity of Resource.
  - People with disabilities and their families can't get services.
  - The majority of people are getting nothing.
  - When people do get services they want everything.
  - The squeaky wheel gets the grease.
- Sliding – People are being pigeon holed rather than given choices.
- The values are getting lost.
- Uncertainty

- Changes can be frightening.
  - Case Managers don't know what's going on and are not helpful to either families or providers.
  - Plan of Care – Case management staff don't know the people they are planning for.
- Cautiously Optimistic
    - Economy getting better.
    - Done well with the legislature.
  - Breakdown of partnerships between county, state and providers.
    - Feels like we are out on a limb.
    - Waivers preventing people with disabilities from obtaining middle class lives – If people make a good wage they lose waiver status.
  - “Block grant funding going away”
    - We seem to be moving to a medical model.
    - Job development dollars in jeopardy.
2. *What do you consider the County's successes in promoting jobs and inclusion for adults with developmental disabilities?*
- Good job at collecting reliable employment data.
    - Legislators like good, reliable data.
    - County benefits specialists helpful and accessible.
  - Funding – In the past the county has kept programs stable.
  - County values employment – King County is the envy of the nation.
  - County excellent at promoting public sector employment.
  - County has always been good at finding flexible funding strategies.
  - Leadership
    - As an employer
    - Finding solutions to problems
    - Vendors have trust in the County – not in DDD or DVR.
    - Legislative Forum – County sponsored forum educates legislators on needs.
    - Support agencies move people from specialized industries to individual employment.
  - County promotes values
    - The value of people working full time.
    - Support for natural supports – County funding is not pulled away when natural supports work.
  - County recognizes the time needed to work with corporations.
  - County technical assistance contract is stellar.

3. *Do you know of supports from the county that have helped people with developmental disabilities in the past that you see slipping away?*
- Everything!
  - Schools are pushing transition students out at age 18.
  - Huge disconnect between school and adult services.
  - DVR and DDD don't work together on funding.
    - Their values are very different.
    - Huge distrust of DVR and within DVR – They are imploding internally.
    - Huge bias in DVR against people with developmental disabilities.
  - Flexible Funding
  - No one knows how it is going to work in January 2005.
  - No one has seen a contract.
  - No meetings about the serious issues facing vendors and people with disabilities.
  - Flexible funding is the key to supported employment.
  - Some vendors hope the system will right itself and that the County will not allow the loss of individual employment. If not, things are going to be really bad for people with developmental disabilities.
  - DDD central office and Aging don't have any idea how supported employment operates.
  - Communication has never been a strong strength of the County.
    - It is critical that, in this time of change and upheaval, the County communicate with vendors
    - Vendors are learning about these changes through rumors.
    - Important decisions that impact services are made without input from vendors.
    - Vendors need to be asked how specific decisions will impact services for people with developmental disabilities.
  - Monthly employment meetings were very helpful. No longer have them.
  - Waivers requirements, Care plans and policies are driving the system instead of people's needs.
  - County's Access transportation services have deteriorated.
  - Residential program quality is uneven. Very few programs.
  - CARF certification requires a tremendous amount of work and has a lot of requirements that impede vendors such as discouraging staff from providing transportation to people with developmental disabilities to get to job interviews. The County did not stand up for vendors and resist DVR's CARF requirement.
  - Technical Assistance
    - Some vendors hear that money is not available.
    - Harder to release people for training due to funding issues.

- Values Training – Some vendors really miss PASS (Program Analysis of Service System) training.
  - Respite and family support are slipping away so employment vendors have to do more non-related employment such as take people to doctor appointments, help people with medications, etc.
4. *If you could wave a wand what would you like to see the County do or change that would improve opportunities for adults with developmental disabilities?*
- Vendors need more money for staff costs and training.
  - Retain County block funding. It is absolutely critical to the success of supported employment.
  - County needs to take the lead in coordination of resources – PASS Plans and DVR (Get away from combat situation).
  - County needs to focus on improving communication:
    - Vendors need to know what is being proposed.
    - Employment data needs to be shared on a regular basis.
    - Vendors and County need to jointly problem solve.
    - Employment Committee needs to be reinstated. It is very important that there be a vehicle for facilitating communication between the County and it's vendors.
    - County should be using vendors as a resource for input and problem solving.
  - County needs to hire or designate a person to deal exclusively with employment issues.
  - County Board Meetings should be revamped and based on the County plan, with information on how the County is meeting plan goals.
  - County needs to publish the employment data again.
  - County needs to convene a local forum to look at new policies and funding changes.
  - Clone Ray.
  - County needs to work to bridge resources between schools and adult resources.
    - Vendors need to get paid for what they are doing in schools.
    - County should advocate for vendors to receive some of the state dollars that now go to schools for transition students.
  - County needs to look at ways of covering some of the administrative costs of vendors rather than just direct hours.
  - County needs to consider paying for staff training hours– Currently, vendors can't afford to let staff go to training.
  - County needs to advocate pulling supported employment out of the Waiver program. It doesn't fit.
  - County and Region should review their strict interpretation of the Waiver.



- County needs to look at how the Waiver interpretation affects people with the most significant disabilities – Vendors can't afford to take people with significant disabilities with the available rate.
- County lobbyist should coordinate with P2020 lobbyist during legislative session.
- County needs to advocate for transition services as a state forecasted program.
  - County needs to work with vendors to understand staff costs and the importance of qualified staff. Staff wages are too low to attract the skills necessary to do a quality job.
  - County needs to look at the cost required to support people with the most significant needs - current rates are insufficient.

5. *Other areas of concern related to employment support for adults with developmental disabilities?*

- Some vendors are tired! – Doing well at educating legislators but keeping up with system requirements is overwhelming.
- Our success is dependent upon our staff – Staff need to know their jobs will be there.
- We need to look at why we don't reward and honor the staff closest to the people with developmental disabilities. Staff have to move up and away from people to make a good wage.
- People with developmental disabilities are getting lost in the maze of bureaucratic requirements.
- Case managers that manage employment and family support should be pulled out of the state and given to the County.

## **Community Protection Providers**

The following summarizes the information from the King County/DDD focus group of providers and case managers serving people with developmental disabilities and community protection issues held in Seattle on December 8, 2004. There were five participants, three residential providers and two case managers.

### **Themes**

The following summarizes the session themes and the participant responses by question. Community protection providers would like to see...

- The County develop new programs to provide employment to people with community protection issues. Most of people with community protection issues are unemployed and need jobs.
- More communication between providers, case managers and County staff. They would like to see a County liaison familiar with community protection issues.
- Providers would like to see the County update the web site to include information on community protection and employment providers that will service people with community protection issues.
- More information and training provided to existing employment providers and County board members on community protection.
- The County explore successes in other counties that are doing well in providing employment to people with community protection issues.
- DVR is reluctant to provide support to people with community protection issues.

### **Summary**

The participants were generally dissatisfied with the employment services in King County. They do not feel the existing employment agencies are interested in providing services to people with community protection and they do not feel the County has put the necessary effort into developing new employment services for people with community protection issues.

The participants believe there is money available to develop new services and would like to see the County talk with several of the counties that they believe are doing a good job in this area.

The participants would like to see improved communication with the County to address the issues facing participants and providers.

The participants appreciate the help they have received from County benefits specialists doing PASS/IRWE as well as Section 8 housing.

## Questions and Responses

### *1. What is a word or a few words that describe how things are going for adults with developmental disabilities and community protection issues?*

- Participant's quality of life is good, but employment opportunities are mostly unavailable.
- Lack of jobs has a huge impact on peoples' lives.
- Couldn't be worse when it comes to jobs for people with community protection - 85% of the people are unemployed.
- King County may be the leader in the nation in supported employment but its record on employment for people with community protection is abysmal.
- Choice of jobs is very limited. People are not performing jobs that interest them.
- Lack of job choices results in people being labeled as not being interested in employment.

### *2. What do you consider the County's successes in promoting services for adults with developmental disabilities and community protection issues?*

- Benefits specialists have been invaluable in King County.
- Specialist on Section Eight housing is very helpful.
- King County is doing nothing right in terms of community protection issues.
- There is nothing about community protection on the King County web site, including programs that are currently supporting people with community protection.
- No effort is being put into this important issue.
- People with community protection issues have funding but aren't being served.
- Pierce County provides much higher quality services for this group of people.
- Pierce County has community protection quarterly meetings with residential, employment, state and county staff to share information.

- Very few client needs are being met in King County.
  - Residential providers and case managers serving people with community protection have no relationship with King County.
3. *Do you know of supports that have helped people with community protection in the past that you see slipping away?*
- Employment agencies that had a negative experience in the past won't serve people with community protection.
  - Organization information on the King County web site has not been updated.
  - One provider used to present at the employment conference in Ellensburg.
  - Arson manual, videotapes used to be utilized. There was more interest in the past from employment providers. Employment providers get frightened.
4. *What do you think are the most important issues facing adults with community protection and their providers?*
- Lack of employment is the primary issue.
  - Barriers to housing due to felony conviction and/or sexual predator status.
  - Washington Protection and Advocacy System has not been helpful to individuals, the main emphasis is to sue DDD.
  - Seattle schools are the worse gatekeepers for students with community protection issues.
  - Transportation is an issue when vendors place people in inconvenient jobs (far away, odd hours).
  - DVR
    - Gate keeping with therapists that reject people with community protection issues as a matter of course.
    - DVR rejects people based on the residential provider. They assume that everyone served by an agency has community protection issues.
5. *What do you think the County could do that would improve services to adults with community protection issues?*
- Organize a community protection conference.

- County should acknowledge who has been referred for employment. Case managers/providers feel that the County ignores referrals.
- County needs to develop more providers willing to serve people with community protection issues.
- Job development needs to be individualized.
- County should explore the successes that other counties are having with their community protection clients, such as Pierce, Thurston, and Clark counties.
- Recruit providers from other counties.
- Allow residential program serving people with community protection issues to provide employment services.
- Employment agency staff needs to have specific training in working with people with community protection issues.
- Job matching is the key – low risk environments.
- People with community protection issues are more likely to be successful and graduate from the program when they have a good job.
- County service providers should be evaluated for the quality of their services.
- Designate a county liaison that will get things moving. Tired of this issue being ignored.
- Quarterly meetings to increase communication and collaboration between:
  - Employment and residential providers supporting people with community protection.
  - DDD case managers
  - County liaison
  - DVR representative
- Discuss successes; best practices; housing issues; past problems and future issues.
- The King County Board needs to be more aware of community protection issues. Providers and consumers should present information to the Board.
- Most people with jobs have very low wages and cannot meet their living expenses. People need living wage jobs.

## Self Advocates

The following summarizes the information from the King County/DDD Focus group of self-advocates held in Seattle on November 29, 2004. There were five participants two whom were employed. The session lasted two hours.

### Themes

The following are the themes from the session and the list of participant responses by question.

- Most of the participants were satisfied with how things were going. They reported having jobs and/or activities that kept them busy.
- The participants said that it is still hard for some people to find and keep jobs.
- Some felt that they had choices in their activities, although they acknowledged that sometimes choices were limited because of the lack of enough staff.
- They wanted to see more opportunities for training self-advocates and staff and to attend conferences like Ellensburg and TASH.
- Participants wanted to see more accessible and affordable housing for people and better transportation services and facilities, such as more reliability in the schedule and posting schedules at bus stops.
- They wanted to see the reductions to services for people with disabilities stopped.

### Summary

Most participants reported being pretty satisfied and felt that supported employment was successful although they acknowledged that for some people jobs are hard to find and hard to keep.

People wanted to see more opportunities for training and conferences and better housing and transportation.

## Questions and Responses

1. *How is it going for people with development disabilities to live and work independently and to be included in community life?*

- Going pretty well. Happy owning a home purchased through the housing trust fund. Active in the Governor's Council on Disabilities and in the community. Does not work because of medical issues. Is concerned about people with disabilities in poverty and without access to appropriate housing, such as people in wheelchairs.
- Pleased with housing and staff support. Very active and involved in hobbies. Has had a lot of choices.
- Good housing now, though has moved around a lot. Active with People First and volunteer activities. Concerned about some people having trouble with transportation and becoming eligible for Access Services. Dental services are not good.
- Going well right now. Lives in own apartment and has had a job for four years. Out in the community a lot and has a lot of freedom. Plans to buy a condominium.
- Had more activity in the community in the past. Lives with three others. Staff reductions have made it hard to do things. Staff were more responsible in the past. Has had a job for two and a half years, but does not like it. Wants to live independently.

2. *What are the County's "successes" in promoting inclusion for people with disabilities?*

- Supported employment.
- Supported employment and community activities.
- Had a previous job with a lot of variety in a workshop.

3. *Do you know of supports from the County that have helped people with disabilities in the past but are now not doing so well?*

- The budget for training.
- Better people running the company.
- Funding for conferences, such as Ellensburg and TASH.

4. *Are there areas of County support of inclusion for people that are not going well and need improvement?*

- Jobs are hard to find. People need more help to find jobs. People need more training. Staff should work more with employers to help people be successful. There is a lot of mistrust between employers and people.

- People should take the time to get to know people and what they need.
5. *Do you think people have choices in what they do during the day, who provides the support and the times and location of the service?*
- No – You need to take what you get.
  - Not in charge of my life. Not able to see my mother enough. There are not enough staff to go anywhere, so there are fewer activities. Some of the people in my house don't want to go out.
  - Have a lot of choices and keep pretty busy.
  - Don't have choices about taking son in the community.
  - Choices are limited by staff, but we can still get out and do what we want.
  - Yes. There are always staff to take us out whenever we want to go.
6. *If you could waive a wand, what would you like the County to change regarding their efforts to promote inclusion, if anything?*
- More accessible and affordable housing.
  - The county should post bus schedules at the bus stops and make sure the bus stops have seats.
  - Bigger buses, especially between 3 pm and 6 pm.
  - Sometimes buses don't come. Sometimes they come early or late.
  - I want to be an actor and a singer
  - I want to get a condo, which looks like it's going to happen
  - I want to have fewer restrictions with my son's placement so he could come to my apartment or stay the night.
  - Stop cutbacks for people with disabilities.



## Case Resource Managers

The following summarizes the information from the King County/DDD Focus group of family members with school-age children with disabilities held in Seattle on November 18, 2004. There were five participants whose case management responsibilities included supporting children, adults and older adults and people who were receiving services from the waiver and people who were not.

### Themes

The following summarizes the themes from the session and the participant responses by question.

- Participants said there are real access problems in the system for many people, such as those not on the waiver, and many services that are no longer available, such as transition funding, attendant care, and community access.
- Case resource managers described an environment that is increasingly difficult. In addition to frozen or eliminated services, they described a “shift” in the past year to a less flexible and more “bureaucratic approach” less focused on the individuals. As a result, families are overwhelmed and staff are burned out.
- They said that there is inconsistent information, for example waiver rules, given to staff and families that causes families to be confused or uncertain.
- The Cares Assessments is viewed as unfair and inconsistent. It does not work well for children or for adults with less significant support needs.
- The participants felt that for many people supported employment providers are not using approaches that result in the person getting a job and gave examples of people who have been waiting a long time to find a job.
- The County has been helpful with support in specific areas such as PASS/IRWE administration, producing the waiver brochure, targeted funding, and maintaining a good database.
- While choices are dictated in the plan of care, choice for many people is decreasing or being eliminated due to rules such as in the waiver or with family support.

- The participants recommended that the County have staff that are connected to individual clients and can attend plan of care meetings. They also wanted to see a more collaborative and proactive working relationship.

## Summary

Case resource managers described an increasingly difficult environment for people receiving services, their families, and staff resulting from increasing limitations in access, loss of choice and reduction or elimination of services.

The participants identified specific areas where County support has been particularly helpful, though said that many people are not getting the help they need to find a job.

## Questions and Responses

1. *What is a word or a few words that describe how you think things are going with respect to children and adults with developmental disabilities?*
  - Haves and have-nots. The current system provides services for people who are on the waiver and those who are not are on a waiting list.
  - Things are going in circles. When you ask a question on behalf of a person or a family, such as about eligibility, you get different answers or no answer, or that things have changed. There is a constant state of uncertainty. This leads to families being confused or uncertain.
  - There is lots of paperwork, but not always what's needed. We get contradictory messages.
  - There is inconsistency in case management due to the lack of training and the lack of information. Again, families get caught in the loop.
  - The interpretation of the waiver rules further hindered by the "chain of command" (e.g. the waiver facilitator in the regional office working with the waiver facilitator in Olympia).
  - Dead-ends. There are some people on the caseload who get nothing.
  - The Cares Assessment creates confusion. There are no clear guidelines and rules.
  - Unfair. The Cares Assessment and plan of care and numerous meetings that families must attend sets clients up and produce nothing. The outcome of the Cares Assessment is often a reduction or elimination in care.
  - Shift in the past year to a bureaucratic approach, less focused on the individual. Families are feeling this. The system is becoming overwhelming to families.
  - Unhappy and burned out staff. There is a huge shift in how it feels to do the job. This is a low point.

2. *Are there areas of support for children or adults with developmental disabilities that are not going well and need improvement?*

- Services are not available at age twenty-one for many people unless there is an exceptional need (e.g. community protection).
- Supports feel like they're "hit or miss". Day program is working for some but not for others. This may be related to families ability to track the system and follow through.
- Family support is no longer available to new families. This program works well but is not available to many. Families are forced to "pick up the slack".
- Housing is not going well. There is a lack of access to housing supports for many people.
- Probably going better for "white, middle class" people that are more connected and have more support. Probably not so good for ethnic minorities or economically disadvantaged people. There is a huge impact at the age of twenty-one if people are not connected to good transition plans and Individual Education Plans.
- There is not much beyond emergency services for people between the ages of three and eighteen.
- Day programs are not working well. The Pathway to Employment does not make sense for everyone. There is less access for support.
- Staff turnover. There is a high rate of turnover at this point. Again, it makes it more difficult for families. There is low morale and staff are demoralized. Performance expectations are creating conflict amongst staff. There is incorrect data used in performance monitoring.
- The Cares Assessment tool does not work for many people. It is not reflective of children or people with less intensive support needs. It does not assess everyone equally. The outcome is mixed, but it is especially detrimental to children and young people.

3. *What do you consider the County's "successes" in providing support and promoting inclusion for children and adults with developmental disabilities?*

- PASS and IRWE support has been very helpful. It's good to be able to connect families to County staff who are informed.
- County staff taking over the budget management and liaison with social services on PASS and IRWE plans has been very helpful.
- Support for the Children's Home team with partial funding.
- The King County data base is very good.
- There are concerns about the integrity of some employment vendors. I question their approaches to supporting clients that isn't leading to employment. An example is a person who has been involved with several vendors, lots of planning including DVR but no positive outcome. The person has been in this process for three years and still has no job.

- Person-centered planning leaves families feeling misled. The process does not yield tangible results.
  - Concerns about the integrity of employment payments. Outcomes don't matter. There is very little outcome at great expense.
  - Concern that we can't "promise" a day program even if funding exists because you can't rely on day programs to follow through.
  - The County has been successful at developing written information that can be given to families, an example being the waiver brochure.
  - The waiver WACs are written in a "user-friendly" format.
  - There should be consistent language use across systems.
4. *Do you know of supports from the County that have helped children and adults with disabilities in the past that are slipping away?*
- Community Access is no longer available.
  - Sheltered workshops. Maybe not "politically correct", but they did serve a lot of people who are now sitting at home.
  - Transition funding. There is confusion about whether funding is available and for whom.
  - Flexibility in childrens supports. The waiver eliminates flexibility.
  - Family support is also losing flexibility.
  - Attendant care is gone.
  - Institutional services are gone.
5. *Do families and adults with developmental disabilities have choices in the services they receive, providers, times and locations that meet their needs?*
- Choices are dictated in the plan of care. People have to indicate in the plan that they have choices. Having it in writing has made a difference.
  - Choices are decreasing or eliminated for many people due to rules around family support and the waiver.
  - Choice between regions is very difficult. There are fewer choices for people with challenging behaviors.
  - Choices exist, but often there are many barriers. Choice is within funding and waiver allowables. There are choices "but"...

6. *If you could waive a wand, what would you like the County to do or change that would better support children and adults and promote inclusion?*

- Every adult with a disability would have the opportunity to be involved in meaningful (to them) day activities every day.
- Somebody at the County who would be a linked to individual clients (i.e. county staff that carried a caseload). The King County data base helps.
- Somebody at the County who would come to a plan of care meeting. We send a letter intended to notify King County and vendors of a plan of care meeting.
- A case manager or representative from the County to represent County services. It's difficult to plan for "wrap around" services when "key players" are missing, especially for kids coming out of school.
- A more collaborative working relationship.

7. *Do you have any other thoughts or ideas you'd like to share that haven't been covered yet?*

- Inconsistent information from the County, which may or may not be intentional, is resulting in a lack of trust.
- I would like to be able to be more proactive than constantly being forced into reacting.
- Always having to react to new rules. There is not enough time to plan, get information, and be proactive. Want to be able to provide better "customer" service. An example is the closing of Northwest Center. We had to go into a "reaction" mode to figure out services for people. There was no opportunity to plan.
- We want to be able to be more "plan-full".
- Want the county to give us "real" information that is better than "sugar-coating it" and not being prepared.
- I appreciate the County asking for our input.

## **School Teachers/Administrators**

The following summarizes the information from the King County/DDD focus group of teachers/administrators who teach in King county public schools at the high school level. This session was held in Seattle on December 1, 2004. There were five participants representing the Seattle, Lake Washington, Highline and Kent School Districts. Teachers who attended the session were a very impressive group, in that they had all developed intensive community based transition programs for students from 14-21 years old.

### **Themes**

The following summarizes themes from the session and the participant responses by question . Teachers...

- Have limited contact with County services and resources but were very pleased with those they have utilized, including:
  - Benefits Specialists
  - Parent Coalition
  - Work Training
  - WISE
- Are frustrated by the lack of capacity in the adult service system.
- Feel that both DVR and DDD often have arbitrary and ever-changing criteria for funding eligibility that frequently translates to no services for their students.
- Are concerned about the increasing numbers of students who do not have jobs after graduation.
- Would like to be able to receive more training on job development and employment training but do not have enough time or resources to attend training.
- Observe that the adult service system in general seems extremely fragmented with no one place to go to receive necessary information.

### **Summary**

Though contact with the County has been limited, the teachers have very high marks for the King County Developmental Disabilities Program.

The major area of concern was lack of resources for graduating students, the lack of information about available services, and the lack of time and resources to attend training.

## Questions and Responses

1. *In your opinion, do you think that there has been progress in the inclusion of students with disabilities in their schools and communities?*

- Yes – Activities are more community based.
- Three out of the four schools participating have transition centers in the community. Students no longer even report to school.
- No – We are physically included but remain as isolated as in the past.
- Peer tutors don't result in friendships with students without disabilities.
- Our students are not accepted as just regular kids.
- One way to predict if students are included in their community is to ensure that they have a job when they graduate.
- Yes – our students are considered a community resource because of the volunteer jobs they perform.

2. *What do you think are the necessary components of a successful transition program?*

- Expertise/knowledge of teachers – including values and commitment.
- School District support:
  - District needs to communicate what they want teachers to focus on.
  - District needs to support teachers and students being in the community
  - District needs to put priority on job development
  - Flexibility with DVR to allow paid employment prior to students exiting school.
  - Good consistent communication with families and teachers about what is possible for students with developmental disabilities to achieve.
  - Good connection/outreach with DVR.
- Components of a successful transition program:
  - Planning – beginning in Junior high School
  - Preparation – for employment
  - Connection with DVR, DDD, vendors, and employers

3. *How has the County helped your students to make a successful transition to community employment?*

- Benefits Specialists have been invaluable.
- The King County Parent Coalition has helped to change parental attitudes toward their children's capacities, not deficits
- Quality employment vendors – need a lot more!
- WISE has worked with students who have not been accepted in supported employment programs.
- Work Training Program.
- Section 8 Housing Specialists.

4. *What are the barriers to successful transition that the County can help you overcome?*

- Fund all of our students. We are tired of transition to no services.
- Provide comprehensive and coordinated information on services. It is difficult to continually hunt for information.
- Fund substitute time so teachers can attend County funded training. Currently, no way to attend relevant training.
- Sponsor monthly transition meetings so teachers can network with adult services as well as other teachers. Transition Councils have worked well in other counties.
- Expand the Work Training Program. Many more students should have this opportunity.
- Increase the capacity of employment vendors:
  - To get involved with our students earlier.
  - To assist with job development so that transition is easier.
  - Work to make employment an entitlement service. Vendors should not be able to decide who gets jobs and who sits at home.
  - Make options available for students who are “not ready to work”.
  - Conduct outreach services to let schools and parents know what is available for students.

5. *Are there other items that we have not previously discussed which you would like to see included in this report?*

- Many school districts have not bought into the need for students to have community-based experiences.
- Why don't schools, DDD, DVR and the County pool resources and blur the funding lines? Students are harmed as often as they are helped by the various rigid and territorial systems.



